

# Methodology of a Family Health Study

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The family health study conducted in 1949 at the University of California represents an experimental effort to design a method of investigation useful in getting accurate and complete information on morbidity and medical care among families.

At the outset, the complexity of factors defining health status was recognized. The objective was set of designing techniques that would embrace the full array of health experiences and would permit the correlation of complicated data on family and personal characteristics, illness, disability, preventive and therapeutic services, and expenditures for medical care.

Previous studies of health experience in the population provide a background for all fresh attempts (1). Many of their techniques and findings were utilized in the development of the experimental method presented here. Past studies, however, often were based upon single interview samples, used complicated schedules, or were restricted to certain aspects of the family health complex.

A new method is sought—one that will minimize dependence upon remote memory, will establish continuous relations between survey sample and research team, and will provide a means of recording and correlating many kinds of interdependent health information.

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Important changes in science and society, which have affected illness and health care, demand new approaches to research in health. Revolutionary clinical advances, new trends in the organization of medical and hospital service, new statistical techniques—all have appeared since the last comprehensive health surveys in the 1930's. Up-to-date information about illness—its incidence and prevalence, the medical needs it creates, the effect upon family economic status—is needed in order to formulate, revise, and administer health programs.

In the family health study, the opportunity existed to test some new techniques and to collect comprehensive data on health experience among a special sample of urban families. This report describes the study population and, in some detail, the methods under trial. It does not present the statistical findings, which will provide a more definitive basis for evaluation of the survey techniques.

## The Population Sample

The study grew out of a health survey conducted in October 1948 by graduate students at the University of California School of Public Health, among employees of the university at Berkeley. In order to compare different techniques, the 4,800 employees were divided into several random samples. One sample, consisting of 815 employees, was surveyed by personal interview and each person was asked whether he would be willing to keep a daily health record for his family in a later study.

Losses from the study sample can be divided into two groups: those occurring before the actual beginning of the study and those occurring

during the study. Table 1 summarizes all changes.

Of the original 815 employees, 160 were not available for the initial interview; 592 (or 90 percent of those actually interviewed) agreed to participate; 63 refused. The problem of sample losses due to employment turnover was a major factor from the very beginning. Sixty-four employees left the university before the initial interview was held in October 1948, and 28 left between the initial interview and the start of the study in April 1949.

Thus, 564 employees and 797 members of their families constituted the starting study population of 1,361 individuals. Over the 5 months of the project 60 employees and 72 family members were lost and 37 family members were gained, giving a final total of 1,266. Fifty-seven of these 60 employees and their 60 dependents were lost through termination of employment; 3 went on leave of absence; death claimed one family member; and changes in family composition accounted for 11. No one who actually started the study refused to complete it, although a few did not cooperate fully.

Characteristics of the study population were compared with available data for the United States, the West, the urban United States and West, and the San Francisco-Oakland metropolitan area.

In general, the study population may be characterized as a relatively young, married, employed, white-collar, urban group with more

females, younger children, and larger incomes than the general population. Its social characteristics were potentially favorable to good health and adequate medical care, but the high proportion of women in the child-bearing ages and young children could be expected to increase medical needs.

### Methods and Materials

The main features of the experimental method were a specially designed family health record booklet, regular monthly interviews by a trained interviewer, and an integrated inquiry into morbidity, receipt of health services, and health expenditures. The booklet was designed to be used at home by the family for daily recording of health experiences, and the periodic interviews with the employee-respondent were held at work. The booklet, however, was kept at work by a number of employees to avoid forgetting to bring it from home on the day of the interview. This practice, of course, interfered with daily recording, but the complication was hard to avoid since the interviews were scheduled at work.

#### *Family Health Record Booklet*

The design of the family health record booklet presented some difficult problems. The record had to include all aspects of family illness and medical care. It had to be simple, orderly, and free from a confusing array of complicated items. It had to encourage complete recording and precision as to dates and dollar values. While language was kept as simple as possible, simplicity often conflicted with precision and adaptability. To some extent, verbal explanations were necessary to mediate between these objectives.

The booklet, entitled "Health Record—Day by Day," was attractively printed. A calendar was provided on the inside front cover for convenience in recording dates of health events. Different page colors were used to identify the various sections of the booklet. The first page presented simple instructions and definitions. A plastic loose-leaf binding permitted withdrawal, insertion, and rearrangement of pages in the event of family changes. The booklet was offered as a permanent possession to the

**Table 1. Changes in study sample, October 1948—August 1949**

Changes	Employees	
	Number	Percent
Total original random sample, October 1948.....	815	100
Unavailable for interview <sup>1</sup> .....	160	20
Unwilling to participate.....	63	8
Willing to participate.....	592	72
Left university before start of study.....	28	3
Sample at start of study, Apr. 1, 1949.....	564	69
Left university during study.....	60	7
Sample at end of study, Aug. 31, 1949.....	504	62

<sup>1</sup> Includes 64 employees who left the university before the interview.

family, the statistical data being transcribed monthly by the interviewer.

Section I, "Family List," was devoted to an initial recording of demographic and social data on each family member—age, sex, relation to head of family, marital status, employment, and health insurance coverage. It was decided not to request income data until the final interview. At that time a separate schedule was completed, which included information as to the existence of a "personal" or "family" physician as related to the family's length of residence in the community.

Section II, "General Health Problems," was devoted to the recording of all underlying illnesses and impairments. Careful memory prodding by the interviewers helped to bring to light the host of chronic complaints, dental and visual defects, partial incapacities, and general health deficiencies so often omitted from health inventories.

Section III, "Health Insurance Coverage," took up an entire page. Although the complexity of public and voluntary medical care plans presented a difficult recording task, efforts were made to obtain data on the name of the plan, duration of coverage, premium costs, and type of benefit for each family member.

Section IV, "Record of Immunizations," comprised the fourth page. Data on past immunizations were collected only for children under 10 years of age. (Current immunizations were recorded for all family members on the monthly record sheet.) A special effort was made to find out where and by whom the immunization was performed, in order to ascertain relative roles of the health department and the practicing physician.

These four sections were filled in during the first visit, with the help of the interviewer. The subsequent sections were designed for daily recording of current health events and were reviewed monthly by the interviewer.

Section V, "Daily Record of Illnesses, Injuries or Disabilities, and of Services Received," was in many ways the heart of the record. Each family member had a separate page for each survey month. Under the proper date, check marks in appropriate boxes indicated days ill, days disabled, and days on which different kinds of home, office, clinic, or hos-

pital care were received. Space was provided for diagnosis or nature of symptoms for each episode. Every effort was made to relate morbidity to service received. Preventive, diagnostic, and therapeutic procedures were identified under the heading "Reasons for Visits."

Much discussion preceded the design of the recording method for duration of illness and of disability. The problem of illness without definite disability was handled by checking separately days of symptomatology and days of at least partial interference with usual activity. In this way, both the subjective designation of illness and the objective experience of disability could be recorded. (See also p. 1154 for discussion of illness and disability.)

Section VI was a "Monthly Record of Expenses for Health Services." One page was used for all family expenditures for health goods and services, since one source of payment for all family members is common and bills for the family are often not itemized. This record included professional fees, hospital charges, money spent for drugs and supplies, laboratory and X-ray costs, and health plan premiums. There were three columns: bills received, individual cash payments, and total cash payments in the month.

Section VII, "Monthly Expenses for Persons Not on Family List," was designed to obtain data on health expenses incurred for institutionalized relatives and others not in the household.

#### *Monthly Interviews*

The monthly interviews, which provided a regular contact between the research staff and the study population, were conducted by two female interviewers especially trained for this project. They both participated in preparing material for the study and organizing the data for statistical analysis.

The interviews were designed to serve many functions. Through them the respondent was to be thoroughly informed and instructed concerning the conduct of the study. Close rapport was to be established with him through repeated visits by the same person. Recordings for the previous month were to be reviewed and corrected; questions were to be asked to elicit

further recall and encourage maximum use of the daily record sheets. The chief operational purpose of the interview was to transfer the booklet data onto transcription forms for later analysis.

The interviewer avoided the questionnaire approach, presenting herself instead as a "consultant" who was available for assistance. Because of the variety of data requested, many cross checks on completeness and accuracy were possible. Discussion led by the interviewer was a vital adjunct to the booklet.

At the first monthly interview, general demographic and health information was collected, terms used and the method of record-keeping were reexplained, and health events already recorded were transcribed. At the final (sixth) interview, the entire booklet was checked against the transcribed record, inconsistencies and omissions were remedied where possible, and, in particular, chronic health problems and expenses were reviewed for completeness.

#### *Preliminary Activities*

A preliminary dittoed draft of the booklet was pretested and modified before the booklet was printed. The study was initiated by sending an introductory letter to each person who had agreed to participate. The letter described the booklet, reviewed the objectives of the study, and explained the role of the interviewer.

A visit was then made to each employee participant, during which a sample booklet was shown and the recording method explained in detail. This initial visit also served to confirm and extend participation by a maximum

number of the original sample. The best time and place for subsequent interviews was determined. A supplemental instruction sheet was felt to be desirable and was prepared to accompany the printed booklet. Through these visits, the final composition of the sample was ascertained. When the printed booklets were received, they were numbered, adapted to family size, and mailed out.

#### **Quantitative Evaluation of Methodology**

Losses from the original employee sample were sizable, numbering 311 out of 815. Of these, 251 left before the study actually began. As previously indicated, sample losses were due primarily to changes in employment status and normal changes in family composition. Relatively few of the original random sample expressed unwillingness to participate, and none dropped out for this reason during the survey. Nevertheless, the employees who did not complete the study, plus their family members, constituted a significant sample loss.

The possibility must be considered, therefore, of bias in the health record resulting from sample losses, even though the original sample is not representative of the general population and the specific statistical findings have only local application.

An exact measure of the effect of these losses must await analysis of the ultimate findings. Meanwhile, the possible bias was estimated in two ways: (a) by comparing employees who completed the study with those who did not, in terms of their morbidity rates as shown in

**Table 2. Adequacy of recording in family health record booklet, monthly average, April–August 1949**

Adequacy of reporting	Number	Percent of all respondents	Percent of those reporting data
Respondents completing study <sup>1</sup> .....	500	100.0	-----
Respondents with data to report.....	405	81.0	100.0
Data completely recorded.....	169	33.8	41.7
Data partially recorded.....	120	24.0	29.6
Data not recorded.....	109	21.8	27.0
Recording of data not scored.....	7	1.4	1.7
Respondents with no data to report.....	95	19.0	-----

<sup>1</sup> Excludes four respondents in families in which another family member was also a respondent and took primary responsibility for maintaining the record.

**Table 3. Adequacy of recording in family health record booklet, by month, April–August 1949**

Adequacy of reporting	Monthly average	April	May	June	July	August
Number of respondents reporting data <sup>1</sup> .....	405	418	425	410	391	381
Percent of these with:						
Data completely recorded.....	41.7	45.7	43.1	38.3	39.1	42.0
Data partially recorded.....	29.6	32.5	26.8	32.7	28.6	26.9
Subtotal.....	71.3	78.2	69.9	71.0	67.7	68.9
Data not recorded.....	27.0	21.1	27.8	27.8	30.0	29.0
Recording of data not scored.....	1.7	.7	2.3	1.2	2.3	2.1

<sup>1</sup> Includes only those completing study.

the previous student survey, and (b) by tracing changes in the age, sex, and marital status distribution of employees remaining over the course of the study to see if the character of the original sample was altered. Unfortunately, data on family dependents were not available in the earlier student survey; therefore, full sample comparisons were not possible.

In the first analysis, three indexes of previous health status were compared: (a) acute disabling illness during the month of the student survey, (b) chronic conditions not disabling in that month, and (c) so-called "health gripes" (conditions causing "irritation or discomfort"). All findings were expressed as percentages of the group in question reporting such conditions. Of these indexes, it was only the first—disabling illness—for which a significant difference was found between employees who completed and those who did not complete the family health study. Nineteen percent of the "completed" group reported disabling illness during the month, as contrasted with 26 percent of those who dropped out. This difference could have arisen by chance less than twice in 100 trials, if both groups came from a population homogeneous as to risk of illness.

Sample losses might thus have resulted in an apparent reduction in the risk of acute disabling illness where no such reduction had actually occurred.

In the second analysis, study of changes in key characteristics of the employee group revealed significant change only as to age, when beginning and end dates were compared. The percentage of employees under 25 years of age dropped from 14.5 percent to 9.1 percent dur-

ing the course of the project. It is inferred from findings of the National Health Survey on the relation between age and disability (2) that such a shift could increase the risk of acute illness, thus tending somewhat to offset the influence of the finding in the first analysis.

The reason for leaving the study was not significantly related to health status at the time of the prior survey. No significant differences were found among those who left the study for various "objective" or "subjective" reasons, or at different times.

#### *Test of Completeness of Information*

A test was performed to see if the repeated interviews used in the study were an especially useful method of securing completeness of data on the existence of long-standing chronic disorders. Findings on pre-existing cardiovascular-renal disease as reported at successive interviews were analyzed. Of the 87 conditions in this diagnostic group, 86 percent were reported at the first interview and 14 percent at one of the five later interviews. Among the 14 percent not mentioned at the first interview were some serious and potentially expensive cases (e. g., rheumatic heart disease). The rapport built up through continuous relations with respondents and the recall value of probe questions by interviewers are felt to have aided in stimulating more complete disclosure of chronic conditions as the study progressed.

#### *Adequacy of Record-Keeping*

Completeness of recording in the special health booklet was evaluated to ascertain (a) whether the recording form, as distinguished

from the repeated interviews, contributed substantially to collection of data, and (b) what circumstances influenced the degree to which the booklet was used.

Completeness could, of course, be checked only against data provided to the interviewer in the booklet or verbally, not against events never disclosed. Each booklet was roughly graded at each visit as having complete, partial, or no recording for the preceding month. If the respondent saved assorted jottings and bills for the interviewer, a "partial" grade was given.

Of 500 employees graded, a monthly average of 81.0 percent had some data to report. Of those reporting data, 41.7 percent entered all of the information in the booklet, 29.6 percent recorded incompletely, and 27.0 percent made no entries at all (table 2). Language difficulties, fear of spoiling the book, and, in some cases, indifference were found as reasons for not recording data, but many of the nonrecorders referred to the order of items in the booklet in making verbal reports.

Factors considered as possible influences on the adequacy of record-keeping were statistically analyzed. The results were as follows:

1. There was no clear-cut relationship between adequacy of recording and willingness to keep the health record when originally approached. Differences in adequacy among those who originally agreed, refused (some who refused the student interviewer were willing to participate when revisited by a survey staff member), or were not contacted until the spring of 1949 were not statistically significant. They could have occurred by chance alone in more than 70 out of 100 trials. Apparently once the employee decided to participate, his original attitude did not decisively influence the adequacy of his recording.

2. Record-keeping declined slightly during the course of the study (table 3). The changes are statistically significant, since they could have arisen by chance alone in less than 5 out of 100 trials. They reflect, at least in part, the difficult period of summer vacations. An upward swing was discernible in the month of September when vacations were over and when final, and especially comprehensive interviews were given.

3. Professional, clerical, and skilled workers

recorded more adequately than service and unskilled workers. Variations in adequacy among occupational groups, shown in table 4, could have occurred by chance alone in less than 2 out of 100 trials.

The main problems were the sustaining of active participation over time and the securing of adequate written records from different occupational groups.

### Qualitative Appraisal of the Method

The following qualitative appraisal of the methods used in the family health study is presented as a supplement to the statistical evaluation. It is based upon the personal experience of the interviewers.

#### *Family Health Record Booklet*

In general, the family health record booklet served its primary purposes well. The significant advantages of the booklet appeared to be the following:

1. Its comprehensive array of designated health items stimulated a fairly complete reporting of family health experiences, even when separate jottings rather than the booklet pages were used.

2. Its daily check-mark system favored the regular recording of current events and aided memory.

3. The attractive design and the offer of the booklet as a permanent family possession encouraged respondents to use it. Other practical uses for the booklet, such as a record for tax purposes, for family budgeting, and for medical reports to the physician, were also discovered.

4. Its scope of information made possible a meaningful approach to family health, since social factors, previous health status, morbidity rates, medical services received, and expenses incurred could all be correlated.

Among the definitions of terms used in the study, those for "illness" and "disability" were the most difficult to apply uniformly. The statement in the booklet limited "illness" to conditions at least partially disabling, that is, producing "pain or discomfort severe enough to interfere, at least in part, with the performance of usual activities, at home, at work, or at school." But the frequent receipt of medical

care for nondisabling conditions and the pursuit of "usual" activities (at least, work) while clinically ill were grounds for broadening the concept. In the final interpretation, explained verbally to the respondents, all nondisabling current health disturbances, all days spent as a hospital patient and at home following discharge, and illnesses disabling during part of their course were included as illness. By checking "yes" or "no" to the question, "Performed usual activities?" days of disabling illness were recorded separately from days of nondisabling illness. Thus disabling, nondisabling, and total morbidity could be tabulated. Individual interpretations, especially regarding preschool children and convalescent periods, remained, of course, to impair uniformity of findings.

The definition of "family" was also important, because it influenced the selection of persons included in the study. A unit based on related persons dwelling together was adopted. This was modified in a number of cases where related adults (other than couples) in the same household maintained independent ways of life.

#### *The Interview Method*

Successive visits by the same person were useful in building up rapport with respondents and in filling in gaps in information. But some employees did not welcome interviews, feeling that they could keep the record adequately without aid and that they could not spare the time.

Interviewing on the campus was economical

of personnel time, both in travel and in the interview itself. Most employees were reasonably certain to be at their jobs at the scheduled time. It is possible that some who permitted this type of interview would have opposed household visits. But in many situations, a home visit might have contributed to more relaxation, privacy, and full attention. A few home visits were made when circumstances required.

Contact with family members, particularly the housewife, would have secured more complete information, at least in some cases. This was not feasible within the limits of this study.

Dramatic occurrences, such as injuries and hospital experiences, were more clearly recalled than minor episodes of illness, routine health services, and details such as exact duration of an illness. In other instances, the obstacle to collection of complete data was unwillingness to disclose family situations, primarily marriage and pregnancy. A few such cases came to light when the critical period in personal life was over and the respondent volunteered information. There may have been other cases where the data were lost.

#### **Summary and Conclusions**

1. The family health study of the University of California was designed to assay a method of collecting information on the full complex of health experience, with less dependence on memory than in interview studies and with

**Table 4. Adequacy of recording in family health record booklet, monthly average, by occupational status**

Adequacy of recording	All occupations	Professional, managerial, official	Semiprofessional	Clerical and sales	Skilled, semi-skilled	Service, agricultural, unskilled
Number of respondents reporting data <sup>1</sup> .....	405	186	89	65	27	38
Percent of these with:						
Data completely recorded.....	41.7	44.7	47.2	40.0	44.4	15.8
Data partially recorded.....	29.6	31.7	24.7	32.3	26.0	31.6
Subtotal.....	71.3	76.4	71.9	72.3	70.4	47.4
Data not recorded.....	27.0	22.0	25.9	26.2	29.6	52.6
Recording of data not scored.....	1.7	1.6	2.2	1.5	0.0	0.0

<sup>1</sup> Includes only those completing study.

maximum correlation of interdependent items. A specially designed booklet kept by the family and monthly visits to the employee by trained interviewers were features of the method.

2. Five hundred and four employees of the University of California and 752 family members were studied for 5 months in 1949. This group had its origin in a random sample of 815 employees. Seventy-two percent of the original sample (or 90 percent of those actually interviewed) agreed to participate. Twenty percent of this group left the university before the study. Sample losses during the study amounted to 11 percent of the employees and 5 percent of the family members. No losses during the study were due to refusals to continue.

3. The study population was atypical; the relatively high proportions of young persons, females, small families, skilled occupations, and high incomes have special implications for health and medical care experience.

4. Evidence on possible bias through sample losses indicates that acute but not chronic illness findings would be affected. Health status did not appear to be a significant reason for leaving the study.

5. Efficacy of repeated interviews in study of chronic disease was tested by analysis of the delay in reporting cardiovascular-renal disease. Though few, the cases discovered in later visits included serious types of disorders.

6. Completeness of individual record-keeping was evaluated. Of respondents with some health event to report, 41.7 percent recorded all data, 29.6 percent recorded some, and 27 percent recorded nothing. Adequacy of record-keeping had no statistical relation to original willingness to participate, declined slightly over the

5 months, and was greatest among professional and clerical groups.

7. Qualitative appraisal of the booklet and of the interview technique, based on the interviewers' experience, reveals that the booklet, despite defects in design and terminology, helped to organize information for the respondent and to secure comprehensive data. The multiple-interview procedure stimulated interest, established rapport, and promoted accurate and complete recording.

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Detailed tabulations not included in this summary report and a limited number of the family health record booklets are available from the School of Public Health, University of California, Berkeley. Data from the student survey, some of which were used for purposes of methodological evaluation of the family health study, have not yet been prepared for publication.

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